

WHEN YOU BOTH HAVE MCS

by Anna L. Cole, MS, and Charles Lee Cole, PhD

The obvious, and major, difference between a household where one spouse is healthy and the other has multiple chemical sensitivities (MCS) and a household where both partners have MCS is that there is no one in the latter home to keep things going during the initial crisis or when either or both have bad days during recovery. Thus, life often seems chaotic and overwhelming, and there is constant stress. The couple must work together, at a time when both are not thinking well and may be having difficulty with irrational feelings, to reduce this stress as much as possible.

Both of us have MCS. Both of us lacked energy and stamina and had frequent respiratory illnesses all our lives, but we, like many persons, thought that everyone felt that way and managed to finish our schooling and to begin productive careers. We married in 1971. Anna's difficulties began in 1974, with hypoglycemia. She gradually learned that it was related to food allergies and by 1980 was beginning to learn about MCS. We had experienced a lot of stress from living with this chronic illness, but we were coping. Chuck's health seemed fine. Then we put new carpeting in the bedrooms in our house, and our lives fell part. Both of us experienced not only physical symptoms but difficulty thinking and managing our emotions as well. Fortunately, we were able to use our training in marriage and family therapy and in marriage enrichment to learn to cope as best we could. We feel that our marriage has been strengthened through the process.

The stresses discussed, of course, are intensified if there also are children in the family who have MCS, as would happen if an entire family became ill because of the toxic effects of new carpeting and other furnishings, home remodeling, or insecticide poisoning. In this article, we will be focusing only upon the effects of MCS on the marital relationship.

One advantage of both spouses having MCS is that you have two persons who really understand what it is like to feel the way you do from reactions to your environment. You may have different symptoms, but you don't have to explain them to your spouse. You also have not only yourself to do the detective work involved in getting well but also another person who may see, hear, or feel different things or may think about these reactions differently from the way that you do. In other words, you can learn to capitalize on your individual strengths and to work as a team.

COPING CYCLES

There are four coping cycles that affect how well you function as individuals and as a unit. In this article, we will refer to these cycles as "both up," "wife up," "husband up," and "both down."

In the both-up cycle, both spouses feel comparatively well, are thinking clearly, and feel pretty well emotionally. This is

the time to discuss strategies for coping with the other cycles, including logistics (how to keep things going) and the emotional atmosphere that you want to develop and maintain.

The second cycle is when the wife is feeling comparatively well but the husband is not, and the third cycle is when the husband is feeling comparatively well but the wife is not. You need to learn as much as possible about how each of you feels, thinks, and acts on a continuum that ranges from being totally disabled to feeling as close to healthy as you can in your state of illness. For example, Anna often wants to talk when she is particularly depressed about feeling ill. Chuck usually doesn't want to talk until he is feeling better. You need to discuss such things as the amount of interaction each wants when he or she doesn't feel well, what essential tasks need to be done by the comparatively well spouse, and how to switch ways of interacting to fit the cycle. Support networks, which we will discuss in the next section, are important during these cycles. Another dynamic that occurs during these two cycles is that during the time when one spouse is underfunctioning, the other spouse has to compensate by doing more, which puts more stress on him or her and may bring about a down cycle.

The fourth, and obviously worst, cycle is when both spouses are not doing well. Even essential tasks may not be completed during this cycle, when survival is the goal. Support networks can be helpful or even crucial during this time. We continued to work outside the home as best we could during the initial crisis stage of MCS. But looking back now, we believe that we would have gotten better sooner had we gone on disability income. The coping strategies are especially important during the both-down cycle. Coping strategies are not enough, however, if both spouses are in this cycle most of the time. You may need outside help with day-to-day tasks.

COPING STRATEGIES

We'd like to share some of the coping strategies that we've developed for ourselves and from working with other MCS individuals and couples. We will focus on the emotional and thinking (cognitive) atmosphere that you need to develop. The number-one goal is to minimize stress, so that you will get better as soon as possible.

Please note that to develop these coping strategies in your marriage you first must have positive feelings toward each other. You may need professional help in clearing out old squabbles and grudges and in dealing with leftover anger and resentments that you have brought into the marriage from the family that you grew up in. It may be difficult to find a psychotherapist who is open to learning about MCS and who has training in working with couples and families, rather than just individuals. Do not work with someone who is skeptical and who believes that you are simply hypochondriacs.

It would be helpful for physicians who treat MCS to have family therapists on their staffs who, because they understood the possible emotional and cognitive effects of EI, could help you not only in learning to deal with your impaired emotions and thinking processes but also in learning the relationship skills necessary to work out the logistics of

following treatment recommendations and in developing the positive emotional atmosphere needed for healing. One or both of you may be too ill to be able to develop coping strategies at first and may have to wait until some recovery has occurred. If this is so, at least remind yourselves that you can reduce your stress by not blaming each other and not taking out your frustrations on each other. Just knowing this may ease some of the tension until you are able to learn more skills.

Persons with MCS have difficulty building and maintaining their sense of self-esteem, because they are unable to accomplish as much as they once could in a society that often places a high value on achievement. As an individual, you must learn to build self-esteem based on simply *being*, rather than on accomplishments or achievements. Being handicapped or disabled does not diminish your value as a human being. As a couple, you must learn to nurture this self-esteem by treating each other with respect and by reminding your partner every day of the qualities that you value in him or her. The development of a mutually supportive atmosphere doesn't happen instantly but by practicing behaviors that will gradually build individual self-esteem and a sense of closeness.

We believe that the major issues facing married couples today are finding ways to nurture both individuality and the sense of "coupleness" and establishing the right balance of these in each marriage. (1) As each of you learns to be your own person and to appreciate your uniqueness, you will enhance your self-esteem. As you appreciate and respect your own and your spouse's individuality, you will be able to interact in a less defensive, more emotionally mature way. You then will be able to achieve a sense of closeness as a couple without feeling smothered. The degree of closeness wanted and needed varies from couple to couple. Some couples prefer to emphasize individuality, while others emphasize togetherness. You need to work out the most comfortable balance for you as a couple. This will occur as you work out coping strategies within your marriage.

First, you must develop a clear, direct, and respectful way of communicating with each other. When you feel ill, you are less able to think clearly and may have problems with depression, irritability, anger, and other negative emotions and may take these out on each other. *You don't have to do this.*

One of the first things that we had to learn is that *with MCS you cannot trust your feelings*. This is the opposite of what most psychotherapy teaches. Your brain is not accurately translating the messages that it receives. Feelings are often distorted and exaggerated, especially negative feelings. Minor irritations may seem like major injustices; remember this about both yourself and your mate. But don't deny or repress feelings, because that won't help you get well, either. Instead, learn to state your feelings in a way that doesn't attack, blame, or put down your spouse. Accept that you, for example, feel depressed, but remind yourself that 1) it would be normal for anyone to feel depressed if he or she were feeling as ill as you do and 2) your MCS is probably intensifying your depression. Then either make it through the down

period by taking care of yourself as best you can and reminding yourself that you will feel better after this period is over, or, if you are well enough, do something to make yourself feel emotionally better. Or, for example, if your spouse is feeling grouchy, accept this, and don't respond defensively to it.

To begin to develop the strategies that will work for you, each of you needs to let the other know, during a both-up cycle, some specific responses that you think would be helpful when you are having difficulty with negative emotions. Then, for example, when the next wife-down cycle occurs, the husband can try the suggested responses. Some may work, and some may not. Remember that the spouse in the down cycle probably won't be rational during these experiments, which means that response changes are entirely up to the comparatively well spouse. Then, at a discussion during a both-up cycle, the husband can share how he felt about what happened and, ideally, the wife will be aware enough to be able to share why parts of the suggested strategy worked or did not work. You then revise the strategy and continue experimenting until it works most of the time. At the same time, you are working on developing a strategy to deal with the husband-down cycle. Remember that each of you is the authority on what you want

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to happen when you are ill and that the needed strategies may be very different.

To learn more about dealing with anger with less stress, you may find Mace (3), Lerner (2), Wile (5), and Paul (4) helpful. As noted earlier, you may need some professional assistance from a family therapist or other mental health professional who understands both EI and working with relationships.

A difficult lesson for us was that sometimes when one of us needs support, the other is not able to give it. This doesn't mean that he or she cares any less for us, but simply that he or she does not have the necessary resources to do so. You must learn to draw on your inner strength sometimes with no help from anyone else.

On the other hand, you must also learn to reach outside of your marriage for help and, as individuals and as a couple, to develop support networks. You may have family and friends in your area who understand and accept MCS. If you do, discuss with each other and then with them how they can be helpful to you. They may be willing to run errands for you, assist in household tasks, and listen when you need to talk to someone. If you are like us, pride often gets in the way of asking for help. Remind yourself that you need to do all you can to get better as soon as possible and that in the future when you are better, you will be able to reciprocate by providing help and support to others who need it. If your friends and family are skeptical and un-

portive, find other persons with MCS in your area through HEAL or your doctor. See if there is a HEAL chapter in your area. We relied a great deal on HEAL members in our area for support and in the early stages talked on the phone almost every day to obtain information and to talk with someone who understood.

You must simplify your life as much as possible. In a crisis stage, you will be able to handle only survival tasks. In the chronic stages, neither of you may be able to handle many household tasks that you once thought essential. Decisions on what to do may be complicated by financial difficulties because of lowered income, high medical bills, and expenses for modifications of your clothing, house, and car. You will have difficulty keeping up with routine tasks such as bill paying, laundry, and routine shopping. You must learn to accept that your life is chaotic and that you cannot keep up with it. You must learn to not blame each other when things go wrong. Try to avoid as much disruption in your life as possible. This is not a good time to make unnecessary major changes in your life. In our experience, many persons with MCS try to keep up a complicated, busy lifestyle, even though this is detrimental to their health.

Learn, as individuals and as a couple, to find joy in your life every day. The most likely place to find joy amidst such stress and chaos is in simple, everyday things. As you slow down and simplify your life, you may begin to find beauty and pleasure that you missed before. For both of us, nature has been a source of joy. We live in the country and can enjoy nature outside our windows when we cannot go outside. You may find joy in everyday objects you use, such as a favorite coffee mug (not used for coffee anymore!), in music, or in the smile of someone you love. At first, you may have difficulty finding joy in all the despair, but with practice you'll have a new outlook on life and what is precious and meaningful about it. You need this joy as a stress reducer, and it is vital to your getting well.

These examples of coping strategies are just the beginning. Some of them may be helpful to you, and some may not. Be creative. Develop your own unique strategies that will reduce stress in the ways in which you interact with each other and that will contribute to a positive emotional atmosphere in your home. □

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